An exploration of the experiences of four women educators living "openly" with HIV in the Ethekwini Region.

By
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DECLARATION

This Masters dissertation represents original work by the author and has not been submitted in any form to another university. Where use has been made of the work of others it has duly been acknowledged and referenced in the text.

The research for this dissertation was performed in the School of Education, University of Kwazulu-Natal. Research was undertaken under the supervision of Dr. Dennis Francis during the period January 2004 to November 2005.

DEDICATION

I would like to dedicate this study to both my late parents, my dad Vernon Myeza and my mom Angeline Baby Irene Khawula-Myeza

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- I would like to thank the Lord Almighty for making this study a success.
- My supervisor, Dr. Dennis Francis, for his guidance and support. I sometimes felt like quitting at difficult times but the little notes that said"hang in there" kept me going.
- My covenant partner, my best friend Paris Senwamadi...for allowing me space to grow.
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- Lastly, and most importantly, I would like to thank the four special women participants living with HIV, for allowing me an opportunity to talk and write about their stories of pain, hardship and victory.

ABSTRACT

My study is an exploration of four women educators' experiences of living "openly" with HIV in their respective workplaces. All four women were from the different geographical demarcations of the Ethekweni region.

I used in-depth interviews, as outlined by Seidman (1999), to learn more about the experiences of the four women. The key findings of my study were (1) the evidence of HIV/AIDS-related stigma and discrimination against people living with HIV, (2) the inclusion of people living with HIV, shown by employers and colleagues and (3) the emergence of a new generation that is better informed, receptive and supportive of people living with HIV.

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CHAPTER 1

INTRODUCTION

When Aids emerged two decades ago, a lot was predicted about it. Its impact was not imagined, even the fact that it could be more harmful than the disease itself. The impact of HIV/AIDS is a challenge not only to South Africa, but also to the whole world.

Discovering one is living with HIV raises fear, not of the health implications as such, but fear of how people are going to react at different levels. Stereotypes, myths and misinformation gives rise to HIV/AIDS stigma and discrimination. This has seen HIV/AIDS shift from being a health challenge to a human rights issue.

To uninformed people, HIV is non-existent and should not be given the attention that it is getting. This denial, pretence and secrecy leads to misinformation that delays combating the disease. While some people are uninformed, others are working very hard to empower and support people living with HIV.

Although studies have been conducted on people living with HIV, no studies on how living "openly" with HIV in the workplace have been done. I therefore decided to conduct a study on a group of women educators living "openly" with HIV in the workplace. More specifically, this study sets out to establish what the experiences are of women living "openly" with HIV, and why their experiences are constructed in such ways.

The word "openly" is used to describe the women because they are open about their HIV positive status. In this study I will use the word "openly" to refer to that unless otherwise stipulated. Three of these women belonged to the South African Democratic Teachers Union (SADTU) support group. I also belong to this support group as I am the regional gender convener. My observation during the interview sessions was that the women were not as open as I would have expected them to be. However, they would later phone and express some of the things that were affecting them personally.

A qualitative research method was selected to conduct this study. This was done in view of the fact that the researcher's intention is to gain insight into the experiences of women living with HIV. For this study, in-depth interviewing, as suggested by, was used. "At the root of the in-depth interview there is an interest in understanding the experiences of other people and the meaning of their experiences". Seidman (1999:3) My interest in this study is the experiences of women living openly with HIV in the workplace and understanding their multiple constructions of reality and interpretation of what it means to be living openly with HIV. Subjective understanding of these women is also my area of focus; hence I opted for an interview as an avenue of inquiry.

The four women participants that I introduced earlier on in this chapter are educators and they all work in the Ethekwini region. They shall be described in the geographical demarcation topic later on in this study. I used pseudonyms instead of their real names during the collection of data and for the purpose of recording and

presenting the findings. Two participants were 35 years old, one was 43 years old and the other one was 54 years old. I agreed to have two interview sessions per participant. These sessions were broken down into one hour thirty minutes for interview one and an hour for the second interview.

I began this chapter by arguing that HIV is not only a health issue but also a human rights challenge. In chapter two I explore literature on women living with HIV globally, locally and in the workplace. The South African HIV/AIDS legal framework is reviewed in this chapter, but the focus is only on that which affects educators because the location of the study is the school and the participants are educators.

Chapter three describes methods used to collect data from the women participants. Location sites and research questions are discussed in this chapter. The experiences of the four women, living openly with HIV, are discussed in chapter four. In chapter five, I conclude by presenting an interpretation and summary of the research.

CHAPTER 2

LITERATURE REVIEW

The first part of this chapter gives an overview of the available literature on women living with HIV globally. Since the study hopes to explore how living "openly" with HIV is experienced in the workplace, existing literature on HIV in the workplace, focusing on women in the South African context, will be discussed in part two of this chapter.

For further relevance, workplace policies and legal framework in the public education sector will be explored in the third part of chapter two. During the review of the legal literature which serves to protect people living with HIV/AIDS from discrimination, it will be seen that there are still obvious gaps in the legal framework, resulting in many problems encountered by HIV-positive South Africans. The fourth part concludes the literature review.

2.1 Global literature on women living with HIV

Openness about one's HIV-positive status exposes one to Aids-related stigma and discrimination. Women in particular suffer a wide range of stigmatization within the context of HIV/AIDS (Aggleton, 2001 and UNICEF, 2001). Women living with HIV/AIDS experience HIV-related stigma and its associated prejudice and discrimination at home, in places of worship, health institutions and the workplace. (Francis, 2003; Francis, 2004; Mthembu, 2003)

This HIV/AIDS- related stigma and discrimination as defined in the introduction, manifests itself in different forms. It presents itself in the form of isolation of people who have the virus (or those perceived to have the virus), in violence, condemnation, ostracization, and termination of service in the workplace (Tharao, 2001; Aggleton, 2000).

Fear of discrimination appears to be worse than fear of living with HIV and how it might affect an individual's health. This argument is confirmed by studies conducted by Aggleton (2000) in India and Uganda, on women living with HIV. He reported that a wide range of different forms of HIV/AIDS-related stigma and discrimination, and denial were identified within the healthcare and employment settings. Discrimination, stigmatization and denial in intimate relationships at home, in the community and even after death (in relation to the disposal of bodies and funeral arrangements), were also reported (Aggleton, 2000).

It was also in this study that inequalities of gender were found to exist, resulting in women being blamed for the transmission of sexually transmitted infection. This inequality in communally-orientated communities is confirmed in Aggleton (2000). That the impact of HIV/AIDS on women is acute, is true, given this argument as cited by Aggleton (2000:7): "Together with traditional beliefs about sex, blood and other kinds of disease transmission, these perceptions provide a fertile basis for further stigmatization of women within the context of HIV".

Webb, (1997:168) argues that, "Sometimes gender determines whether the person infected with HIV gets support or negative reaction from society. Women and men have different roles and responsibilities in a patriarchal society and as a result they have different needs and interests". Gender, in this case, refers to socially defined

identities and roles assigned to women. It is always argued that gender roles are socially constructed, therefore they can be changed. Women living with HIV still seem to be experiencing different treatment as opposed to men living with HIV.

This noted stigma and discrimination found in studies conducted in the global village on women living with HIV also reveals a "spoiled identity" inherited by the women once they are known to be living with HIV. Further isolation from the community is often the result. Verbal accounts from different women living with HIV reveal that they are aware of the social identity change as decided by their communities. When their identity changes, the affected people use that new identity to form another group to support each other.

O'Sullivan, explaining this shift and formation of the new group writes: "The support group came into existence and became the platform to sharing experiences and making their specific needs and aspirations known. These support groups later gave birth to women uniting across the globe to advocate and demand their rights as women living with HIV/AIDS" (O' Sullivan, 2000:26).

The literature explored so far is relevant to this particular study, given its location and the questions it seeks to answer. The description and the purpose of the support group as given by O'Sullivan will be evident later in the study when the sample group is discussed.

A UNICEF (2001) study conducted in India, Ukraine, Burkina Faso and Zambia, revealed that stigma manifests itself in the form of rejection, gossip and taunts. HIV-positive women suffered from self stigma, withdrawing themselves from the public eye. In the workplace, leave was sometimes imposed on them, making their sickness

invisible. In some cases in the same UNICEF study (2000), people living with HIV were reported to be keeping their HIV status secret in the workplace. If their status became known, they experienced rejection by colleagues and excuses were found to dismiss them from their jobs. Some employers enforced pre-employment testing. The UNICEF (2001) study blames these reactions on fear, misinformation and already existing negative reactions to people living with HIV. Findings, causes and impacts revealed in Aggleton (2000) and UNICEF (2001) match, even though both were conducted on different sites.

2.2 South African literature on women living with HIV

Literature on women living "openly" with HIV in South Africa was difficult to find. This difficulty in accessing studies on people living with HIV is described by Francis (2003:60) as "silence of people living with HIV". This is in part due to fear of discrimination. HIV/AIDS-related stigma, discrimination and denial were revealed in studies on the South African situation. (Mthembu, 2000; Francis, 2003; Tallis, 2000; Sunter and Whiteside, 2000). Like the studies conducted in the global village (UNICEF, 2001 and Aggleton, 2000), South African women living with HIV feel the need to come together and share their experiences as they face common challenges. Quoting O'Sullivan (2000:25), Francis writes: "Now we want to put our own voices, experiences, hopes and fears on the agenda. Our numbers are growing and it's increasingly that we have to organize together to change the conditions of our lives".

Francis (2003) conducted a study on people living with HIV in the North Durban region. Participants comprised four African women, one white woman, two African men, one white man and one Indian man. Their experience of discrimination ranged from negative labels, stereotypes, unprovoked attacks on individuals and property,

institutional discrimination and exclusion, to internalized HIVism. Francis, explaining internalized HIVism writes: "As people accept negative views of themselves and experience feelings of guilt, shame and self blame, internalized HIVism occurs" (Francis, 2003:68).

Changes in the workplace in terms of interpersonal relationships, was also noted in Francis's study. One participant responded by saying, *"They would talk very softly with one another but when I joined they would keep quiet. I knew they were talking about me and I noticed that none of the other colleagues were using the toilet that I was using and that my tea cup was placed away from the other cups."*

Francis (2003) concludes his study by saying that the manifestation of HIVism creates a climate of harassment and discrimination that forces many living with HIV/AIDS to live their lives as second-class citizens. Consequently, many people living with HIV/AIDS still live in fear of discovery because of the prevalent stigma and the associated prejudice and discrimination. I agree with this argument based on the fact that few people are open about their HIV-positive status, but statistics confirm that a bigger percentage of people are living with HIV than recorded.

My study refers only to educators, but raises the question of why this global silence persists amidst this rising pandemic. Buckenham (2000), and Francis (2003) both agree that HIV impacts negatively on women and that women experience gender-based violence because of their known status. Verbal responses from participants in their studies stand as evidence of how badly the participants were treated by families, friends, partners, employers and co-workers. One participant in Francis (2003:63) said: *"He (boyfriend) did not say anything, he just left. He returned at about eleven and returned drunk. He then started hitting me. My mouth was bleeding. He said that*

I was going to give him the virus. He threatened to burn me so that I will not infect him anymore or anyone else."

Whether the global village or South Africa is being referred to, the response to people living with HIV/AIDS is the same and all depends upon information acquired about the pandemic.

In the film "*Yesterday*" a South African production, evidence of stigma, discrimination and denial was portrayed. Yesterday was a married woman with one child. She lived in deep rural KwaZulu-Natal, while her husband worked in the mines in Gauteng. She was perceived by her neighbours as having HIV when she developed a persistent cough. She was later diagnosed with HIV and went to inform her husband in Gauteng. Her husband responded violently and assaulted "Yesterday". At home in KZN, "Yesterday" was later joined by a very sick husband. Local rural women chased them out of the village because of their "spoiled identity" and fear of being infected. They later relocated to an isolated place where the husband eventually died.

Women in this film were portrayed as having colluded with their own oppression, allowing society to decide who to support and who not to, based on their own gender and limited knowledge of HIV. The hostility displayed by women to another woman known to be living with HIV is explained by Pharr (1998:10) as horizontal dynamics and she explains, "If one has learned self-hatred because of one's membership in a minority group, then the disrespect and hatred can easily extend to the entire group, so that one does not see hope or promise for the whole. It is safer to express hostility towards other oppressed people than the oppressor".

This film relates to my study for a number of reasons, one being because of its location; one participant in the study works and lives in deep rural KwaZulu-Natal. My concern though, after watching this film, was that of the transmission of the silent curriculum through movies and media reports and their impact. Where HIV/AIDS is concerned, and precautions are not taken, teaching of fear, misconception and re-enforcement of prejudices cannot be avoided.

I read two easily accessible newspapers; *Sunday Sun* and *Umafrika*. Reporting on the death of a well-known artist, Welcome Msomi, a reporter wrote: "AIDS slowly snuffed out life from his ravaged body" (*Sunday Sun*, 14.11.2004). Another headline read: I-Aids igawule indodana ka Mandela *(Translation: AIDS chopped Mandela's son)* (*Umafrika*, 17.01.05). Both reports pronounce fear of the disease which might lead to different reactions. Another poignant example is one of the 1999 reports during World AIDS day. Gugu Dlamini was captured coming out with her AIDS status and was later attacked and killed by a mob of angry neighbours for shaming their community. This incident sent a clear message to others living with HIV that disclosure can be dangerous.

2.3 Women living openly with HIV/AIDS in the workplace

Again, sourcing literature on this topic was difficult, but a local magazine reported a story about a woman who is living with HIV in her workplace. This again raised the question of why there is no documented literature on people living with HIV in the South African workplace. Again, fear of being known to be living with HIV, because of other's bitter experiences, seems to be the barrier.

Florence Ngobeni is a researcher who lives "openly" with HIV in her workplace. She does not experience any discrimination based on her status. (*Oprah*: 2003) Connie Setjeo owns a company called *Setjeo and Associates*. Her company focuses on equipping companies to manage HIV in the workplace. She is living "openly" with HIV in her workplace and is an author and poet. She writes:

> *"Contributing my story to the voice of South Africa was both healing and fulfilling in a sense that I had to go back down memory lane to dig up some of the painful moments and experiences of life, and hold them in my memory in order to put them onto paper. I experienced joy when I looked back at the ugly end of things and saw how I have started all over again and turned into something beautiful."* (Setjeo, 2003:18)

Delarise Mulqueeny, a Portnet employee living openly with HIV in the workplace, writes: "*These disclosures on my first day made me see there were more people afraid of their own status. This day was an eye-opener for me. I was exposed to ignorance of the disease, insensitivity, sadness and mixed emotions all in one day*". (Transparent, Summer 2003:19).

It is not clear what made the three women decide to be open about their HIV status, but not encountering the problems already cited in this chapter might be what encouraged them to open up. Their types of workplaces may have been another contributing factor. What makes the women in *my* study different from Connie Setjeo is the fact that she is an employer in her own company and it is easy for her to write and to implement workplace policies. In Florence Ngobeni's case, her exposure to information on HIV/AIDS might have triggered her to be open about her status, hoping to challenge more people in the workplace. The women in my study only

depend on how much the other workers and their communities know about HIV and the protection offered by the Acts and workplace policies on HIV/AIDS.

I agree with Mthembu's view on disclosure as she says, "It has been stated that disclosure is a double-edged sword. On the one hand it may be constructive and enable people living with HIV/AIDS to get support and services that they need... on the other hand it can be quite destructive. Some women with HIV are chased out of their homes when they disclose their HIV status. Others lose their jobs, and many are denied employment after telling health workers that they have HIV". (Mthembu, 1998:27)

2.4 The South African HIV/AIDS legal framework and its effect on educators

The International Labour Organization (ILO) estimates that between 2000 and 2020 the South African labour force will have decreased by 17%. Furthermore, worker illness and deaths will affect employment by increasing cost and reducing revenues.

Employers will be required to spend more on health care, burial, training and recruitment of replacement employees. The advent of HIV/AIDS has brought with it new manifestation of discrimination, namely unfair discrimination on the grounds of employees' HIV status. It is reports of this nature that scare some employers into wanting to test people before offering them employment. This in turn jeopardizes opportunities for some people who are not aware of the so-called fitness and health test.

I am going to use the *Jacques Charl Hoffman vs South African Airways* case as an example of an event that transpired in our South African workplace in 2000. Mr. Hoffman, the appellant, is living with HIV. He was refused employment as a cabin

attendant because of his HIV-positive status. This case was heard on 18 August 2000 and was awarded on 28 September of that year. The appeal concerns the constitutionality of the South African Airways (SAA) practice of refusing to employ a cabin attendant living with HIV.

In September 1996, the appellant applied for employment as a cabin attendant with SAA. He went through a four-stage selection process comprising a pre-screening interview, psychometric test, a formal interview and final screening process involving a role-play. At the end of the selection process the appellant, together with eleven others, was found to be suitable for employment. The decision was however subject to a pre-employment examination, which included a blood test for HIV/AIDS.

While the medical examination found him to be physically fit and thus suitable for the job, the blood test showed he was HIV positive. He was subsequently informed that he could not be employed as a cabin attendant in view of his HIV status. The appellant challenged the constitutionality of SAA's refusal to employ him in the High Court, alleging that the refusal constituted unfair discrimination and violated his right to equality, human dignity and fair labour practice. The relief granted was instatement of the appellant (Whiteside and Sunter, 2000).

The above is an example of unfair labour practice on the part of the employer, by ignoring the existence of chapter two of the South African Constitution, which cannot be superceded by workplace policies. The South African Constitution states: Everyone has a right to fair labour practices." There are also more general provisions such as the right to equality and non-discrimination (s9), and privacy (s14)

The Labour Relations Act 66 of 1995, referred to in the case cited earlier, protects an employee with HIV/AIDS from dismissal on the basis of living with HIV. However, where there are valid reasons related to the capacity to continue working, and fair procedures have been followed, their services may be terminated in accordance with section 188(1)(a) This Act was irrelevant to this particular case given the basis that it refers to people already employed, not people looking for employment. The same year the Minister of Labour launched the *Code of Good Practice* on key aspects of HIV/AIDS and its relation to the Employment Equity Act. This code serves as a guide for employers and employees. It is not legally binding on all employers and its adoption in the workplace is voluntary. However, the parts of the code dealing with non-discrimination, pre-employment testing and confidentiality may be legally enforced.

This law is relevant to the education system as it protects people living with HIV/AIDS. Its aim is to protect educators from experiencing all forms of discrimination listed, given the fact that educators have chances of being promoted to higher post levels, and living with HIV can jeopardize such chances.

The Basic Conditions of Employment Act 131 of 1998 (BCEA), states that every employee is entitled to six weeks paid sick leave within every cycle of three years. Furthermore, provision is made to negotiate extensions of leave but at a reduced rate (provided it is less than 75% of ordinary rate of pay). This provision is likely to be important for employees with advanced HIV disease or AIDS. As good as the offer seems, there may be more danger of involuntary disclosure. This is because there is no privacy for educators who take frequent leave from work, and when it gets to the stage where an educator has to be medically boarded, the employer conducts their

own medical investigation in terms of procedure. This can force the candidate to disclose, or rather have his or her status known by the employer, thus forfeiting the right to voluntary disclosure and confidentiality.

The National Policy on HIV/AIDS for Learners and Educators in further Education and Training Institutions connects educators with their community in addressing HIV/AIDS. This connection includes community-based organizations, other government departments and faith-based organizations. The support of learners and educators living with HIV or ill with AIDS is guaranteed should they want to continue attending school. Again, as good as the policy seems in theory, a big question remains to be answered: Are communities ready to deal with having an educator who is living openly with HIV?

The vagueness of these policies is that they do not clearly articulate disciplinary measures that will be taken against people who oppose this law. Baxen (2005) in Shisana, Peltzer, Zungu-Dirwayi, Louw and Louw, 2005:116) writes:

> "Messages and knowledge about HIV find expression in complex discursive spaces where, for example, male and female teachers are not necessarily treated fairly and justly. It is also within these spaces that teachers have to interpret their personal and professional roles, responsibilities and lived experiences. It is also within the complex spaces of home, school and community where teachers have to work, live and respond to the pandemic, a space unaccounted for within policy."

The Department of Education Workplace policy for HIV/AIDS review, as argued by Simbayi (2005), can be further complicated if the individual teacher is already living with HIV and intends living openly with HIV.

I facilitated an HIV/AIDS workshop in October 2005 for female educators who specialize in the foundation phase, a very crucial phase in schooling. I asked a class of 60 educators from the Ethekwini region what legal framework and policies on HIV they knew of and they responded in Zulu saying, "*Yini loko?*" (What's that?)

This response was strange to me because all, or most, educators belong to a union and unions have agreed nationally to contribute towards combating the pandemic. I consulted union policies but could only find two policies from two of the recognized unions in South Africa. The South African Democratic Teachers Union (SADTU) and National Professional's Teachers Organisation of South Africa (NAPTOSA) have clear policies that are informed by the Bill of Rights of the South African Constitution. Both policies were created in line with the Department Of Education National Aids Policy. They both guarantee non-discrimination, equality, privacy and confidentiality. The policies referred to are good on paper but the concern is whether these policies are known to the affiliates and are being implemented. If they are, why then are there still so few people who are living openly with HIV in the education sector?

2.5 Conclusion

This chapter attempted to expose the reader to existing literature on women living with HIV around the world and locally. Mounting evidence of stigma and discrimination in different contexts was indicated. Existing workplace policies and

Acts on HIV/AIDS were reviewed and it is clear that there are loopholes that need fixing. In the next chapter I describe the research strategy I used to engage a group of women educators living "openly" with HIV.

CHAPTER 3

METHODOLOGY

3.1 Introduction

In this study, I, as the researcher, have read about how people living with HIV and those perceived to be living with HIV, have been treated in different contexts. Belonging to a support group of people affected and infected by HIV/AIDS made me think that listening to individual experiences was going to be very easy. Unfortunately, this was not the case.

Having chosen the topic, getting participants for my study was very easy. Scheduling interview sessions was also an easy task, as will be noted in the interview discussion later in this chapter. The first meeting outlined my research objectives and what was required of the participants, and was followed by the first of two interviews, but it was during their second interviews that 'all hell broke loose', reminding me that HIV is a serious issue.

This second set of interviews for individual participants took place over a period of six days. The last two participants became very emotional as they related how badly they were treated as a result of their positive status. The worst case, for me, was related on the last day when one participant spoke of how she contracted the virus through the cultural practice where her late husband's brother took over as her partner when her husband died. As an African woman, this practice needed no explanation to me as the researcher, as I am well aware of it.

The participant relating her story said: *"Everyone in the family knew he had AIDS. I was the only one who was not told but encouraged to accept him as my husband. That is how I got infected."*

Having said this, she started crying, and I found myself crying with her. She held my hand as she wiped tears from *my* eyes, while at the same time offering *me* teas at *my* office. As she made tea, she bravely said, "We can't turn back the clock now; life has to go on". I learned that as a researcher, you sometimes fail to divorce yourself from the feelings of the participant.

I felt overwhelmed during the data collection and this time I dumped my data (I can't recall for how long), until my supervisor reminded me of the deadline that I had failed to meet for submission of my raw data. I therefore psyched myself up and reminded myself that the road to completion of my study was a long route and that meant I would have to deal with this data for a long time, analyzing and discussing it, until such time that it is presented in the form of a thesis.

Qualitative research must place parts of social lives into a larger whole, or the meaning of the part may be lost. For example, it is hard to understand what a baseball glove is without knowledge about the game of baseball (Neuman, 1991:331). I was reminded of this argument while compiling my report. Having collected data, I thought about the attachment that is coupled with the task of connecting parts to form a larger whole.

The next task in the study was to review the raw and recorded data, and this meant I had to go back to the data I had stored. Listening to tapes and double-checking what I had recorded to see if there were any loopholes, was also a trigger. Some information I had missed was recorded on tape. This clarified that all four participants had had emotional experiences but the tones were different. I had not realised the impact of unconscious reporting. Neuman (1991) argues that some events appear to be insignificant and not worthy of being reported. He further states that a detailed re-reading of notes looking for negative cases reveals overlooked events.

This chapter is going to discuss the following: methodology, type of study, research sites, samples, data collection, accessing data, the research instruments and data analysis.

3.2 Methodology

Cresswell (1998) in Imel, Kerk and Wonacott (2002: 2) defines qualitative research as, "an inquiry process of understanding based on distinct methodological traditions and enquiry that explores social or human problems. The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants and conducts the study in natural settings".

I am going to follow suit in this study and adopt qualitative research as a means of meeting the research requirements. As previously mentioned, this study seeks to expose how four women living 'openly' with HIV experience their lives.

3.2.1 Type of study

Butcher (1902) as cited by Seidman (1991) argues that as Aristotle tells us, every whole has a beginning, middle and an end. In order to give details of their experiences a beginning, middle and end, people must reflect on their experiences. I therefore chose the in-depth interview in this study to collect data. I felt that interviewing was the best method of inquiry because the study deals with people's experiences, and people's language or the spoken word is the best means of relating their experiences.

Seidman (1991: 3), explaining this phenomenon, writes, "Interviewing then, is a basic mode of inquiry. Recounting narratives of experience has been the major way throughout recorded history that humans have made sense of their experiences". Regarding the interview, Seidman shares the view that to understand human behaviour means to understand the use of language. These views influenced the decision to choose interviews for this study. A semi-structured guide was therefore put together to assist me in conducting the interviews.

3.2.2 Research site

The Ethekwini region in the south of KwaZulu-Natal was chosen as a field site. As previously mentioned, KwaZulu-Natal has recently emerged as the leading province in terms of HIV statistics for educators, with more than 20% reported as being HIV positive. Infection rates were found to be highest among women between the ages of 25-34 (Shisana, Peltzer, Zungu-Dirwayi, Louw and Louw: 2005).

Geographical districts were spread over the Ethekwini region. The four sites are therefore a combination of urban, urban informal, urban formal and deep rural. Geo-

locality of residence in all four participants was the same as geo-locality of the schools where the participants were based. All four sites differed socio-economically in terms of infrastructure, availability and accessibility of information-providing resources.

All four sites are historically African residential areas, where different religions and cultures are observed. I, the researcher, am a resident in the semi-urban township of Umlazi, situated in the south Ethekwini region. I am a grade three educator, institute support team coordinator, and serve as a regional gender convener for the Durban South region of the educators' union, SADTU (South African Democratic Teachers' Union).

3.2.3 Research sample

Given the nature of the topic which specifies "women educators living openly with HIV", individuals interviewed were selected on the basis of these stated characteristics. Purposive sampling, as suggested by Seidman (1991), was used. Patton (1989) in Seidman (1991) suggests several approaches to be utilized to achieve a purposeful sampling, including *typical case*, *critical case*, *convenience sampling* and *maximum variations*.

For the purpose of representation of the larger population in the Ethekwini region, participants were selected from different geographical districts as mentioned in the sub-topic dealing with sites. Tagg (1985), in Seidman (1991:3), when discussing maximum variation sampling, writes, "The range of people and sites from which the participants are selected, should be fair to the larger population. This sampling

technique should allow the widest possibility for readers of the study to connect to what they are reading". As I am a first-time researcher, the fear of handling heavy data resulted in the limiting of participants to four.

3.2.4 Accessibility

Accessing the participants was made easy by the fact that I work on the gender desk dealing with AIDS programmes. I am also a member of SADTU's support group, which seeks to assist all educators affected and infected by HIV/AIDS in terms of prevention, care, treatment and support. It was noted at these support group meetings, during sharing sessions, that women members were not using the already-created avenue to share their experiences with other members. They were therefore not benefiting from these combined sharing support group sessions.

As a social justice student, I felt the need for this research as I wanted to find out why these women were silent about their experiences when part of a support group comprised of both sexes. I therefore tried to address this problem using a gendered approach to the support group programmes. Tallis (1997) argues that gender sensitive programmes recognize the perceptions and interests arising from women's different social positions and gender roles. "Programmes that are gender sensitive and attend equally to specific needs (both strategic and practical) of women and men would contribute to a sustained change in sexual behaviour" (Tallis, 1997: 59).

Using what had been noted by Tallis's point of view, I approached 16 women belonging to the support group. During a women-only session, I presented the study I intended conducting and the response was positive. Seven women willingly agreed to

participate. It was a struggle to reduce the number to four (a manageable number of participants for a small 32-credit dissertation). The geographical district criteria became the determinant of who to exclude. Those that fell short of the criteria were debriefed and they accepted their exclusion from the research. Unfortunately, I was left with three, instead of four participants.

I therefore approached a woman educator from deep rural Umkomaas whom I had supported when she was dismissed from her workplace on the basis of her known HIV status. She gladly agreed to participate in the study. Mthembu (1998), Tallis (1997) and O'Sullivan (2000), warn, in their literature, of the sensitivity and risks of being perceived to be living with HIV, let alone having the AIDS virus. Surprisingly, all the participants were not only willing to be known to be living with HIV, but also wanted to share their experiences.

3.2.5 Research instruments

3.2.5.1 Data Collection

As the focus of the research is other people's stories, in-depth interviews allow participants to freely narrate their experiences as the interviewer asks them, using the constructed questionnaire. To collect data from the participants, I used face-to-face interviews, given their benefits in terms of allowing flexibility, observation and the ability to use two types of recording (as explained earlier in this chapter). Moreover, HIV is a very sensitive issue and the nature of this topic could not allow telephonic interviews. Eisner (1991), Hull (1997), Mitchell and Sablinksy (1999), Merriam (2002) and Nasser (2001) in Imel, Kerk in Wonacott (2002), argue that qualitative research occurs in natural settings, typically examining a small number of sites,

situations and people over an extended period of time. This motivated me to opt for face-to-face interviews at the SADTU office, which is familiar and central to all four participants.

The aim of listening to these participants is to create meaning from stories that people have constructed from their experiences. Seidman (1991) advises that at the root of the in-depth interview is an interest in understanding the experiences of other people and the meaning they make of that experience. Hull (1997) concurs with Seidman on this view.

To make it possible for me to collect data, two interviewing sessions were scheduled for individual participants. These two sessions excluded the first meeting where I met all four participants to discuss the research and their rights, for example anonymity, confidentiality, legalities and their right to withdraw (as suggested by Seidman (1991)). Two participants felt no need for anonymity when I discussed the use of pseudonyms to protect their identity. Their argument was that they were living openly with HIV anyway. I made them understand that I had no control over the thesis once it was completed and explained the necessity for anonymity.

Interview one for each participant then followed, with a one day break between all four participants. The questions were constructed in such a way as to assist the participants in telling their stories in a particular pattern. Some strong emotions were noted as the women told their individual stories, and they were allowed time to express their emotions and then compose themselves. We therefore could not keep to the one hour and thirty minute session we had previously agreed on at our first

informal meeting. The relationship that had been created by our belonging to a support group resulted in participants seeing no need to complete a consent form. Despite this, I insisted they complete the consent form. Interview two, for all participants, was more interesting because women spoke more freely, giving their own interpretations as to how their individual experiences were constructed.

3.2.6 Processing of data analysis

Interviews were taped as per verbal agreement with individual participants. Notes were also taken during the interviews to assist me to reconcile audio and written data for the purpose of accuracy in terms of recording. The recorded and written data were coded and pseudonyms were used as codes for each participant.

3.2.7 Analysis of biographical data

The four participants in this study are African women educators living openly with HIV. I used the word "openly" to describe the openness of these women about living with HIV in the workplace and their respective communities. The ages for these women ranged from 25-54 years. All four women are employed by the Kwazulu-Natal Department of Education as educators.

Zama* aged 35, lives in an urban area north of Ethekwini. She is widowed but remarried to her brother-in-law. She has two children, both boys, who are HIV negative as they are from her previous marriage. She is pursuing part-time studies as an AIDS counsellor and teaches at a primary school.

Zethu* aged 35, lives in a township south of Ethekweni. She is widowed with one son. She is a high school educator.

Nonsizi* is a 43 year-old widow from an urban informal area situated about 15 kilometers from the city of Durban. She has three daughters that she is raising alone in a nuclear family setting. Nonsizi teachers at foundation phase level.

Zemvelo*, 54 years old, was separated from her husband for five years. They have since reconciled and are living together with their two daughters in deep rural Umkomaas.

*Not their real names.

Name of participant	Age	Marital Status	Geographical district	No. of children
Zama	35	Remarried	Urban	2
Zethu	35	Widowed	Township	1
Nonsizi	43	Widowed	Urban informal	3
Zemvelo	54	Married	Deep rural	2

Table 1: Biographical data of participants

3.2.8 Limitations of the study

The sampling in this study limits representation of the real population. This was done purposefully to make silent voices heard, using as much data as I could possibly get. Tallis (2000), gendering the responses to HIV/AIDS, argued that mainstreaming is

useful in providing opportunities to bring the isolated voices into the power base of society. Reporting on this research is richer and more detailed and this is termed as a "thick description" when coupled with narration and quotations.

3.2.9 Researcher and participant bias

My position in the union could result in false answers, more specifically in the participants' responses. This is because the participant might be seen as giving militant responses to impress the union leader, (myself).

3.2.10 Reliability and validity

To ensure reliability and validity of the research, research instruments such as audio tapes and notes taken during the research are kept as evidence.

I conducted all the interviews. The use of one interviewer meant that the possibility of misunderstanding or misinterpretation was minimal.

Finally, I maintained ongoing debriefing sessions with my thesis supervisor to explore some of my implied assumptions, to review the emerging methodology, and to articulate my feelings and reactions to the various aspects of the study.

3.2.11. Conclusion

This chapter has attempted to expose the reader and the researcher to personal experiences of the participants, while attempting to employ recommended means of conducting a qualitative study. Findings will be discussed in the next chapter.

CHAPTER 4

PRESENTATION OF FINDINGS

4.1 Introduction

In this chapter, I will discuss themes that emerged from the data collected, through interviews, from the four women participants in my study. Relevant published literature reviewed will be used to support the results of my study.

4.2 Family context

Families have a major role to play in terms of care-giving, emotional support and sometimes psychological guidance to family members in general. It is more serious when a person has a challenge like HIV. Some families have become places where rejection is experienced. This happens because families fear the stigma that is attached to having a "sick" person in their family. In some cases rejection and fear is due to lack of education about HIV/AIDS. Two of the women participants experienced pain, hurt, rejection and threats from their families when they disclosed their HIV-positive status. *"My husband started beating me and accusing me of bringing HIV into our lives" (Zemvelo)*, and *"I feared for my life when he suddenly became violent"*, (Nonsizi) were two of the responses.

Husbands and partners have their own fears, determined by how the community and their families are going to react to the issue. Some of this denial and anger is taken out on women in the form of violence. Buckenham (1999:30) writes, "In South Africa, women are contracting HIV in numbers higher than men. Where a woman is found to

be HIV positive, open discussion with her partner provides an opportunity to prevent infection, to discuss the consequences of children, and to plan for the future".

Despite this, the women in my study experienced scorn, rejection and violence. This argument explains the participants' responses:

> *"The guilty are always afraid. He (husband) knew exactly who the culprit was. He feared the community, and due to frustrations, he became violent and he beat me. I am sure he was beating AIDS, not me." (Zemvelo)*
>
> *"My husband's first comment when I confronted him about bringing AIDS to our relationship was 'I thought you wanted it; that's why I gave it to you.'" (Nonsizi)*

Families in the participants' lives can be divided into two categories: biological family and the in-laws. These families seemed to differ in terms of handling the cases of women living with HIV. Two participants had this to say about their biological families' responses:

> *"My mother was very supportive of us. She is there the whole time to offer help and advice." (Zethu)*
>
> *"Though testing HIV positive has affected my two brothers who are my only surviving relatives, they are very supportive and protective of me." (Nonsizi)*

It was noted, however, that the in-laws proved to be finding it difficult to accept daughter-in-laws who were living with HIV. Two of the participants said,

> *"His (husband's) family cared very little about us and our deteriorating health. They only visited us on month-end to collect their share." (Zethu)*

"I had to put up with pushy in-laws who wanted a baby out of the relationship knowing very well the risks we were at." (Zama)

Another participant could supply another experience: "*My Moslem in-laws blamed me for infecting my husband when all in all it was vice versa. I tried to convince them I was hurting when my husband was still in the hospital. They barred me from seeing him in hospital. When he died, I was not informed and they held a private funeral. I wonder why this turned into a race issue.*"(Zethu)

A study conducted by Webb (1997) in KwaZulu-Natal communities, reveals that psychological support for people living with HIV will come primarily from the immediate family, in contrast to a possibly more hostile community. This gives a clear distinction between biological and family by marriage (who forms part of the community).

Not only do the women experience rejection, their children also live in fear of being stigmatized. The following are experiences suffered by two participants:

"My daughter heard through the media that I was expelled from my workplace because I was living with HIV. She could not face the scorn and rejection from other children and she left boarding school before things got out of hand." (Zemvelo)

"My children are struggling to come to terms with the whole ordeal, made worse after losing their father through an AIDS-related illness." (Zama)

Many cultural practices in various societies place women in disempowered positions. The imbalances between men and women are recognized as contributing factors to women's excess vulnerability (Karim, 1998:15). This has led to many women being economically, culturally and socially disadvantaged. One woman participant gave this account of the cultural practice she had to go through when her first husband passed away. "*My late husband's brother had the virus but did not tell me when he took over as my next husband.*" (Zama)

Lamond (1995:18) explains, "There are also many cultural practices in various societies, which traditionally place women in disempowered positions. Polygamous marriages are still common practice, as is the brother of a dead man taking over the latter widow under his care and protection".

O'Sullivan (2000:250) maintains that until women have power to live their lives, they will remain vulnerable to HIV infection. She further argues that although the root of women's vulnerability lies in the imbalance of power between men and women, biological and sexual practices play an important role in a more efficient transmission of HIV in women compared to men.

While one participant was infected with HIV through a cultural practice that is well-known in the African community, another participant was struggling with the birthright issue, which in the African community is decided by in-laws instead of being agreed upon by the couple involved. Aggleton (2001) says that being outside the structure of power and decision-making, they (women) may be denied opportunities to participate equally within the community, and may be subject to

punitive laws, norms and practices exercising control over their bodies and sexual relationships. This participant stated, "*I had to challenge my culture and express our decision surrounding the baby issue. I therefore became an outcast at family gatherings. I was no longer recognised as part of the family*". (Zethu)

4.3 Experiences within the school environment

4.3.1 Relationships with management

People known to be living with HIV/AIDS in the workplace experience exclusion, discrimination and termination of work contracts. (Aggleton, 2000; Francis, 2003). One participant, who experienced expulsion from her work because of her known HIV status, gave this account:

> *"My principal (male) could not put up with my condition and the school governing body (comprising of men only) could not deal with the sick me who had made headlines with my HIV dispute. I was suspended from work without pay when the Department of Education discovered, through print media, that I had AIDS. My salary was docked and I had to live without any income." (Zemvelo)*

There *are* policies in place, the Labour Relations Act 66 of 1995 and the Basic Conditions of Employment Act 131 of 1998, to name two. These Acts aim to protect people living with HIV in the workplace, but the above woman participant (Zethu) still experienced stigma, discrimination and expulsion, merely because she was known to be living with HIV. This account reveals how dangerous irresponsible media coverage can be to people's lives, especially where HIV is concerned. Power and status is sometimes misused to make decisions about junior employees without

following the proper channels of dealing with individual cases. Power imbalances on the basis of gender and position (principal vs junior staff member) jeopardized this woman educator's future.

However, some managers emerged as supportive of the women participants once they disclosed their HIV-positive status. Two of the four participants did not have a problem at their respective schools. They described the following reactions:

> "*I got a supportive response from the staff and my senior management (mostly women). I get counselled and help when needed*" (Zama)

and,

> "*My good principal is very supportive. She goes all out to make me feel I am still important. She shares with me all the useful information concerning AIDS*". (Nonsizi)

4.3.2 Relationships with colleagues

HIV/AIDS-related stigma manifests itself in different forms; some people experience it in a form of rejection and lack of support from friends and sometimes colleagues. Two participants gave accounts of how they were treated by other workers:

> "*To them (colleagues) HIV is a disease of the prostitutes. They are aware of my track record concerning relationships. They promised to support me, but when I have to be hospitalized, it becomes a problem getting one of them to move in and take care of my children. They are scared of living in a house whose owner they are aware has AIDS.*" (Zethu)
>
> "*AIDS to them (educators) is a disease of lower class, not educators.*"(Zemvelo)

Since HIV emerged two decades ago, a lot has been said about it, and most of it is untrue. There have been a lot of myths and stereotypes surrounding the subject. While the origins were being traced, prostitutes were blamed as the people who were spreading the disease. Prostitution is a stigmatized profession, hence the class division among women themselves.

This contradiction between verbal support promised initially and real support, is perpetuated by stigma and fear of death. The colleagues referred to are educators who are expected to be educated, progressive and better informed about AIDS, especially transmission of the virus. Another participant also had a problem with the support she was promised by her colleagues and she responded, "*They are very supportive of me and when I have to stay away from work they visit me and take care of my duty load. I am aware though, that behind my back some of them are saying 'Why doesn't she go for medical boarding?*'(Nonsizi)

The study conducted by Francis (2003) reveals that participants who were open about their serostatus in the workplace experienced exclusion, discrimination and even sometimes termination of their working contracts. This holds true for the experiences of the participants in my study.

4.3.3 Relationships with learners

Learners referred to in this study come from different feeder communities who share different views and have different teachings about people living with HIV. Most of the communities' views are negative and one would expect learners to react

negatively to being taught by educators who are living with HIV and are open about their status. Despite the participants' experiences being mostly negative in families, with other colleagues and senior managers, it was noted that learners accepted educators rejected by the same communities. Participants said:

> *"I received letters of support from different schools in Kwazulu-Natal. Learners at my school were initially confused (by my ill-treatment at school and in the community), but gradually they understood"*. (Zethu)
>
> *"I enjoy teaching learners about this reality called AIDS. They give me their undivided attention, ask clarity-seeking questions and applaud my bravery. I receive cell-phone messages from them and letters and cards with personal messages. I identify with a number of them who look very healthy but are living with HIV"*. (Zemvelo)

Learners seem to differ form their communities and some of the educators, in terms of relating to people with HIV. Webb (1997:162) applauds this diversity and willingness to learn and co-operate with educators living with HIV when he says, "Education programmes targeting the young ones are thus having some positive effects". Given the positive responses from the participants, a stigma-free generation seems to be emerging through this group of learners who are taught by educators open about their HIV status.

4.4 Experiences within their own community

The way in which we see the world and our thinking, is strongly affected by the environment we live in. We come to accept things as natural, when in reality they are based on injustice, inequality and exploitation. Our thinking is strongly affected by

our class, race, social position and experience. "Most communities, due to fear, ignorance and not wanting to deal with relevant, issues and challenges of HIV/AIDS, turn a health issue into a human rights issue." (UNICEF, 2001; Webb, 1997) Two participants had this to say about their communities' attitudes about HIV/AIDS:

> "*The community that I work for thought only prostitutes could get HIV. Prostitutes are perceived as dirty people and this makes HIV a dirty disease that can never affect educators*" (Zethu) and,
>
> "*They have different views and ideas about HIV and I feel they need a lot of teachings about HIV/AIDS. Nasty jokes are told about people living with HIV*" (Nonsizi)

The perceived origins of HIV in this case become the determinant of community response to these women's challenges. It tampers with the way educators are viewed by the community. The influence of the environment that people come from makes it impossible for people to make individual decisions about people living with HIV. Francis (2003: 122) writes, "People with HIV were living with the knowledge that they must fear random unprovoked attacks on property". This is substantiated by one participant who told how she "*lived in fear when the community threatened to burn my house*".

It was made clear from my research that how individual communities react to individual HIV cases depends solely on information that community has acquired about HIV. It is so unfortunate that the incorrectness of information is not weighed until it affects certain individuals. One participant had this to say about her community:

"Most people in my community are educated and they responded in a positive and supportive way. Other community members, more especially the illiterate people, are very rude to people living with HIV. They use ugly words like "simnandi" (we are nice), we are suffering from "iqhoksi" (high-heeled shoes). (Zama)

"When you approach a group of people on the street, you can see that they are gossiping about you, but when you get closer, they stop talking until you have walked past, then the conversation resumes. You try to ignore that but it is hurting". (Nonsizi)

The variance in responses to the disease is striking and shows how the community responses to the disease are based on different frames of experience and reference (Webb, 1997:165). Stigma, stereotypes and myths surrounding HIV/AIDS is noted in the different communities in this study and they vary per individual community. Most of these negative responses were harmful to the four women living with HIV and contribute to the stresses with which these women have to live.

One participant said, "*I was attacked and assaulted by local community members who had read the Zulu newspaper that reported, 'Lixoshiwe ithishelakazi elinengculazi' (a female teacher with AIDS has been expelled). They (the community) felt I had brought shame to their place of residence. We were living in fear of being attacked at home when we received threats of damaging our property*". (Zemvelo)

The tendency of dominant groups (people who are HIV negative or assumed to be) to stereotype people with HIV is prevalent in this case. This has turned her into a target.

Tharrao and Massaquio (1996: 75) argue that "the stigma associated with HIV/AIDS and the social construction of the disease has created a distancing effect in the communities that have long been blamed as its originator. Stigma, with its subjective notions of shame, disgrace and cultural misinterpretations, results in a *spoiled identity*".

4.5 Gender and HIV/AIDS

That women are perceived to be the only transmitters of HIV/AIDS was revealed in studies conducted globally and locally (UNICEF, 2000; Aggleton, 2000; Buckenham, 1999; Webb, 1997). The term mother to child transmission (MTCT) is one example that illustrates HIV is transmitted mainly by women. The term does not refer to the role played by both partners in terms of HIV transmission. An alternative term, parent to child transmission (PTCT) has evolved in recognition of the role and responsibility that both men and women have in protecting themselves and their families against HIV infection UNAIDS (2001) as cited in UNICEF (2002). One participant gave an account of the differential treatment meted out to women living with HIV.

> "*His family hated me and blamed me for giving their son HIV*". (Zethu)

From the participants' stories, a question emerges that is commonly asked; who infected who? People tend to concern themselves much about the culprit as if the answer is going to bring home some form of cure or relief. It is strange, though, because the transmission is always perceived to lie with one partner, the female. There is this tendency to want to blame the woman as is evident in my research study.

Explaining the gender bias in terms of transmission, Ingstad (1990), Mushingeh, Chana and Mulileka (1999), and Thant (1993) as cited in Aggleton (2000) argue that, together with traditional beliefs about sex, blood and other kinds of disease transmission, the perception provides a fertile base for further stigmatization of women within the context of HIV. All four participants had experiences that confirmed this:

> *"I was the bad woman who infected my husband and I carried all the blame."(Nonsizi)*
>
> *"After doing a record check, the community thought I was the one that brought HIV to our marriage."*(Zemvelo)

> *"My in-laws are from the old school of thought and they saw women as child-bearing objects and I became a suspect when we told them we had HIV."* (Zama)
>
> *"I met one of my ex-boyfriends and he was uncomfortable with the condition that he was in. I gave him a lift and disclosed my HIV-positive status and spoke to him about the challenges and how I am coping. He was very quiet and looked upset and said nothing about his being sick. A month or so later he called me, disclosed his also-positive status and he went on to thank me for helping him back to life. He confessed to hating me initially, thinking I had infected him and it is then that I told him exactly how and when I got HIV. He apologized."* (Zethu)

One participant recalled how her being a woman affected her position in the workplace:

"My principal was my husband's friend and you could feel and see that he ill-treated me because he was sympathizing with my husband". (Zemvelo)

Webb (1997:168) argues that sometimes gender determines whether the person infected with HIV gets support or negative reactions from society. Their cultural background leaves women with little or no chance to debate simple basic things, for example the use of a condom or any form of prevention, with their male partners. This concern about who infected who cited earlier hinders progress in terms of treatment, care and support as it becomes a determinant as to whether or not to support a woman living with HIV. Two participants related:

"To my community, I am seen as a bad woman who not only infected but also killed her husband. I, as a result, do not get the sympathy other widows are getting."(Nonsizi)

"My being friends with the local pastor was interpreted by church members as wanting to infect their leader. This leaves me bitter and with no option but to isolate myself". (Zama)

The powerlessness, marginalization and violence experienced by all four women participants in my study are sufficient evidence to illustrate the differential treatment of men and women living with HIV.

4.6 Horizontal sexism

Explaining why horizontal dynamics exist, Pharr (1998:10) writes, "If one has learned self-hatred because of one's membership in a minority group, then the disrespect of hatred can easily be extended to the entire group so that one does not see hope or

promise for the whole. It is safer to express hostility towards other oppressed people than towards the oppressor". One participant gave an account of how her relationship with other women at work was affected when the decision that had been taken by the male principal and school governing body was supported:

> "*For fear of associating themselves with a bad woman, they kept quiet and watched me suffer. It was painful to get negative treatment from other women; anyway they finally learned their life lessons*". (Zemvelo)

This participant experienced horizontal sexism. This type of oppression is experienced when members of an oppressed group mistreats others who belong to the same oppressed group, in this case mainly because they are living with HIV and this makes them belong to the "other" group. HIV/AIDS has created division amongst women with the purpose of reinforcing internalized oppression. Internalized oppression is effective in keeping oppression in place because it divides the oppressed. There are many ways in which women compete, as one participant describes, "*Most of the jokes told at my workplace are about how Miss X used to be proud and how smartly she used to dress up and how funny she now looks in those expensive clothes. The clothes hang on her as if they were hung on a coat hanger. Other women tell all these jokes about women*".(Zama)

This is an example of how HIV-related stigma has perpetuated further divisions amongst women and results in horizontal sexism.

4.7 Gender roles and responsibilities

Men and women are socialized into different roles and responsibilities in a patriarchal society, and as a result, they have different needs and interests. This means women living with HIV get different treatment to men living with HIV (Aggleton and Warwick, 1999) as cited in Aggleton (2000). In communally-oriented families, the well-being of the family supercedes all rights of the individual. Of the two types of needs in a family set-up, namely practical and strategic, the women are socialized to focus more on practical needs.

Housework, for example, in most communities is seen as women's work, and so is care-giving. Tallis (2000:60) argues that women are given little formal and informal support and are expected to carry increasing burdens of care-giving. One participant shared how she nursed a sick brother while she herself was very sick:

> "*My brother, who was a lecturer at Zakheni College, died of AIDS in 1998 and I was care-giver until he died. This affected me very much; I was very sick and I was also grieving the loss of my three other brothers who had died through violence. I felt like I would be neglecting him if I sent him to a hospice. As the only surviving relative, I took on a heavy task. He finally passed away and I was devastated. I nearly died; actually internally I died.*" (Zemvelo)

This explains why women sometimes forget their health problems and focus on caring for their families, in the process putting their health at risk like this participant did. The gender inequality emanating from the status of women in society, the anger, blame and violence that is cited in Karim (1998), Pendry, UNICEF (2001) and Webb (1997) are the same as those experienced by some women participants in this study.

4.8 HIV-related discrimination at the hands of medical practitioners

AIDS-related stigma is further complicated by other socially discrediting characteristics of the group most affected by it. Visible minority group membership, homosexuality, drug use, commercial sex work and poverty are all characteristics that carried significant negative social connotations prior to the epidemic, and now have become associated with AIDS. "The racist discourse that dominated the first decade of HIV and personal experiences with racism remain major factors in the continuing silence and increase in HIV infection among African women and their communities. Once diagnosed with HIV, one cannot escape the socio-cultural interpretation attached to it, creating negative implications for the individuals, for the social interaction and for their relationships" (Tharao and Massaquio, 2001:73).

This is what one of the participants had to say about how people are quick to display racism towards people living with HIV:

> "*He (Indian doctor) failed me and his approach was that of a busy man who could not sympathize with a dying woman. He pronounced a death message and told me to look for a good lawyer and write out a will. Hopefully they (doctors) are clear enough today on how to break shocking news like this one. I was just another African woman with AIDS*". (Zemvelo)

It is interesting how death cannot be separated from HIV/AIDS. While one participant was perceived to be dying by her doctor when she tested HIV-positive, another one had a different race-related encounter and she responded:

"*My two male Indian doctors mishandled me, and it was a racial issue. To them I was just another black woman who was gong to die of AIDS and they encouraged me to fulfill my in-laws' wishes and have a baby, promising to support me in my pregnancy. They were just going to use me as part of their statistics in their research*". (Zama)

As much as the participants felt that they were discriminated against by their respective doctors on a racial basis, I believe it was institutionalised examples of stigma.

4.9 Professional identities

Finding out that they were living with HIV/AIDS challenged the women in different ways. Their social status was affected and they were left with a "spoiled identity". The women themselves come from a community that stigmatizes people living with HIV or perceived to be living with HIV.

Testing HIV positive, coupled with the challenges encountered by all four participants, encouraged them to do something, and being educators, they used teaching as their base for transformation. After testing HIV positive, this is what they had to say about their teaching:

"*I do justice when it comes to teaching sex education. I see to it that I find out from each and every learner if they have a sick person at home, which is very common these days in our feeder communities. I always use HIV/AIDS as a cross-cutting issue in my teaching. We also talk about dealing with grief and*

what death is, with my young learners. They have a lot to share about death, irrespective of their ages."(Zama)

"*Universal precautions concerning blood issues have become a daily lesson to my young learners. I teach them tolerance and the importance of caring for others, irrespective of what their condition is.*"(Zethu)

"*Being a walking and a living testimony has encouraged me to teach the truth. I tell it all as it is and feel good thereafter. Whenever I do my reflection for the day, I always check if I did justice in terms of empowering learners about AIDS.*"(Zemvelo)

"*I was able to reach out to other AIDS sufferers from various workplaces, being an AIDS focal person for the Education Department. What made me influential was the fact that I identified with the people.*"(Nonsizi)

Schools aim to teach writing, reading and life skills. The outcomes-based curriculum sets out to produce a lifelong learner who is confident, independent, multi-skilled, compassionate, respectful of the environment and able to participate fully in adult life. The curriculum looks at the needs of the individual community and tries to address them. This means that teachers are charged with teaching concrete data as well as other skills to enable the learners to develop accordingly. What the participants in my study are imparting to the learners, is often reflected unknowingly and unconsciously. They are using their challenges and bitter experiences to educate learners, and in the process benefit the communities in terms of transforming mindsets about HIV and stigmatized groups.

All four participants share the same challenges and fears with people that are affected by, and infected with, HIV. As one participant shared, "*It happened to me and I do not want it to happen to somebody else*".

4.10 The support group

The support group in my study has become a place where people that are infected and affected by HIV, meet. One participant defines it as, "*SADTU has been a home to me since 1996. They have given me all the love and support and have taught me to love, care and support other people in worse conditions than myself. I have a family in the union called a support group, where I am free to share my feelings with the people that I trust and they are there for me most of the time. Our support group is a healing platform for us infected and affected by AIDS*". (Zemvelo) It substitutes the home and family that was discussed earlier in this chapter and it differs from it.

What makes the support group different from the real home and family is this belonging emanating from the fact that people in the support group identify with each other and this keeps them together. One participant said, "*I joined SADTU a few months ago after attending their support group a number of times, irrespective of not being their affiliate. I identify with a number of those men and women and it feels good to share experiences with other people, some of whom have been there longer than me. I receive free counselling, attend relevant workshops and have access to medication. I have also learned a lot about the AIDS legal framework*". (Zama)

Men and women emerge as equal in the support group and what concerns men concerns women too. One participant said, "*I have been introduced to a SADTU support group by my colleagues and have attended their meetings. What I noticed and was impressed to see is that both male and female comrades lead the programme. HIV/AIDS has been for a long time a woman's problem*". (Zethu)

Karim, (1998:23) argues that given the powerful role of men in society, HIV/AIDS interventions and strategies targeting men will have an impact on reducing the vulnerability of women to HIV. The need to shift the balance of power, within relationships and society, between men and women, remains paramount. The presence of men in the SADTU support group is seen by one participant as a shift from the normal.

The inclusion of non-affiliates who are living with HIV means that HIV is taken seriously in the union and it sees no comrade; instead it unites people in the workplace. The involvement of males means that some men have been empowered on HIV/AIDS and they emerge wearing a gendered lens. They might still be few, but these few can be good influences on the rest.

4.11 Conclusion

The issues raised in this chapter confirmed that there is still HIV/AIDS-related stigma and discrimination in the workplace, at home and in the communities, and that HIV impacts more negatively on women than on men. However, learners in the context of the participants seemed to be more tolerant and accepting of the four participant educators living with HIV. It is evident from the findings that this new generation

differs in how they relate to people living with HIV. The findings also suggest that the four participants have benefited from the supportive structures set up by SADTU for people living with HIV. The support group was seen as a solution to the isolation and alienation that people living with HIV/AIDS had experienced.

In the final chapter, I will present a general conclusion which may be of help in further research.

CHAPTER 5

SUMMARY, INTERPRETATION AND CONCLUSION

5. 1 Introduction

During the study, many findings emerged, and I felt the need to use this chapter to summarise those findings using the following themes:

5 .2 Exclusion

HIV/AIDS-related stigma was prevalent in this study. It manifested itself in different forms, for example isolation in the workplace, violence at home, views that the infected person should be medically boarded, neglect and betrayal by friends, and expulsion from work. One participant lost her teaching job because she admitted she was living with HIV.

The four women's experiences of sexism could not be ignored. This was noted when the respondents gave their frame of reference as to why they were ill-treated at different levels. The patriarchal roles and responsibilities still prevailed, despite the deteriorating condition of some participants. This left the women participants stigmatized and discriminated against, not only on the basis of their HIV status, but also on the basis of gender.

Some health care institutions and personnel appeared to not be informed in terms of handling HIV issues, given the sensitivity of the matter. As a result, some participants experienced mishandling, interpreted by participants as racism.

The church emerged as another negative influence where individual HIV/AIDS cases were concerned. Fear of how the church was going to react when a participant disclosed her positive status, was evidence that HIV-related stigma and prejudice prevailed in some churches. This could create a problem in rural communities who rely on the church to set norms and standards for living.

Cultural beliefs and practices stood out as a tool that complicated issues where HIV/AIDS is concerned. The practice of taking over a brother's wife if the brother dies and non-negotiability of safe sexual practice was the reason one participant became infected. Inheritance of the deceased's estate was more important than the health of the surviving female spouse. Pressure from the in-laws to have children, despite the known HIV-positive status, is also part of these practices. The interconnection between religion, culture and HIV also emerged as a determinant of the exclusion of one participant by her in-laws.

Denial about the disease itself from participants themselves, was noted.

Three out of the four admitted to not knowing about the disease before they discovered they were living with the virus. Some families living in denial responded by displaying hatred towards the person they thought had brought the disease to the relationship.

Gender-based violence was experienced from partners who could not deal with the challenge positively. At the home level, female family members were found to be

supportive, whereas partners (men) were in denial and some used violence. Less support was received from the in-laws, compared to biological immediate families.

Lack of knowledge where HIV/AIDS is concerned could not be accounted for, despite the prevalence of the disease in communities. Gaps were noted in terms of the correct information about HIV/AIDS. In some cases it was ignorance that led people not to acquire already-existing information; in other cases it was illiteracy or believing what people had already learned and the unwillingness to unlearn. This saw the educators involved taking on a huge task as transformational leaders, to empower people around them. These negative social responses encountered, led the women to a struggle to de-stigmatize HIV in the workplace and in their communities. They struggled for acceptance from families, work acquaintances, children, husbands and the community in general, with their goal of inclusion.

In the workplace, there were contradictions between verbal support and practical support from colleagues. This was caused by lack of knowledge of the transmission of HIV, and fear in general. Willingness to learn about HIV/AIDS in the workplace was, however, noted, although in most cases it was due to the pressure of having a person living openly with HIV, being infected or affected by, HIV at work.

5.3 Inclusion of people living with HIV/AIDS

Support in the form of relevant information was made available at some schools. Some managers were perceived to be doing a good job in seeing that the individual got the help he/she needed. These workplaces were seen as HIV friendly and where human rights were respected, as soon as the individuals disclosed their positive status.

The support group which was termed as a home to the participants supported them in terms of prevention, treatment, care and access.

5.4 **Recommendations:**

In South Africa there is a project that is currently being run by the recognized unions and the department of Education called Prevention, Care and Treatment Access (PCTA). This programme seeks to address HIV & AIDS related stigma, discrimination in the workplace and promotes care and support. Programmes like these should be supported, monitored and be evaluated by all stakeholders involved. Another study of this nature in two years time will be recommended.

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NFORMED CONSENT FORM

Living with HIV/AIDS

Dear Participant

My name is Nil-desparandum Nokujabula Myeza. I am a student at the University of KwaZulu-Natal. I am currently engaged in completing my M. Ed degree. As part of my degree, I have designed a research study to explore the experiences of women living with HIV/AIDS in the Wentworth area. The study is being conducted under the supervision of Dr. Dennis Francis. Should you have any queries, you are welcome to contact him telephonically at (031) 2603490. Your participation in this study will help by creating a better understanding of the experiences of women living with HIV/AIDS in this area. Please consider the following:

- ✓ As part of the study, I am going to ask you some personal questions. Your answers will remain totally confidential.
- ✓ Whilst the information you provide during these interviews will be included/used in my thesis, your name and the names of the people you mention, will not be used in connection with any of this information. Your identity will remain anonymous.
- ✓ The questions will be divided into two interview sessions. Each session will last approximately 90 minutes and will be tape-recorded.
- ✓ You do not have to answer any questions you do not wish to answer and you may end the interview at any time you wish to. However, I will greatly appreciate your total contribution since this will give me insight and help me to understand your unique experiences as a woman living with HIV/AIDS.
- ✓ You may ask to listen to the audio-tapes or view the transcripts at any time. However, these will remain my property.

Would you be willing to participate? Yes/No _____

I. _____ have read the above statements and do hereby

agree to participate in this study of my own free will and under the conditions set out above.
Please contact me if you have any further questions or concerns. My contact number is: 0724618451.

_____

_____

Participant's Signature Date

_____

_____

Researcher's Signature Date

INTERVIEW SCHEDULE

Interview One

This interview will attempt to establish or elicit information on participants past lives, early socialisation and the experiences which culminated in the participant's HIV-positive status.

Questions:

1. How old were you at your last birthday?
2. Which religion do you subscribe to?
3. Have you ever attended school?
4. What is the highest level of schooling that you have completed?
5. How long have you lived in Wentworth?
6. Have you ever been married?
7. What is your understanding of HIV?
8. What is your understanding of AIDS as an illness?
9. What is your understanding of how HIV is transmitted?
10. When were you diagnosed HIV-positive? Tell me about the experience?
11. Tell me about the experiences that led to you being positive?

Interview Two

This interview will attempt to establish or elicit information on participant's experiences, perceptions and feelings in the context of HIV/AIDS.

Questions:

1. Is your family aware that you are HIV-positive?
2. Tell me about how they found out and their responses to this news?
3. Have you disclosed your HIV status to any members of your community e.g. your

neighbours, friends, children's educators or people at your place of worship?

3. Have your children been affected in any way by your HIV status?
4. Tell me about their responses?
5. Do you know about or belong to and/ or benefit from any HIV/AIDS support group/s in the Ethekwini region area? Tell me more?
6. Tell me about your experiences with regard to visits to the clinic or hospitals?
7. Are you currently employed?
8. Are your employers or colleagues aware of your positive status?
9. Tell me about their responses?
10. What would you like to tell the community or society about HIV/AIDS?
11. Do you wish to make any other comments about your experiences, feelings or thoughts in relation to HIV/AIDS?